

PALLIATIVE CARE FOR CHILDREN IN LOW- AND MIDDLE-INCOME COUNTRIES

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Palliative care is an important component of a cancer control programme. There is a lack of access to children's palliative care in many low- and middle-income countries (LMICs), yet the need is great. Whilst there are challenges to the development of children's palliative care many of these can be overcome, and the basic principles for cancer control can serve as a framework for the development of children's palliative care in LMICs.

Palliative Care for children is an essential component of any cancer care programme. Whilst aiming for early identification, treatment and cure is a priority, in many instances this is not possible, particularly within low- and middle-income countries (LMICs), where 70% of all cancer deaths occur (1), and 80% of individuals with cancer present at an advanced stage, with limited or non-existent resources available for prevention, diagnosis and treatment (1). The incidence of childhood cancer is increasing globally, with an estimated 300,000 new cases diagnosed each year: 215,000 (0–14 years) and 85,000 (15–19 years), with many more cases uncounted and unreported due to a lack of childhood cancer registries (2), and approximately 90% of these children live in LMICs (3). As a core component of cancer control, palliative care meets the needs of all patients requiring relief from symptoms and their families (1).

What is palliative care for children?

The World Health Organization defines palliative care for children as a special, albeit closely related field, to adult palliative care:

- ➔ Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- ➔ It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- ➔ Health providers must evaluate and alleviate a child's

physical, psychological, and social distress.

- ➔ Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- ➔ It can be provided in tertiary care facilities, in community health centres and even in children's homes (4).

Whilst this is the definition recognized globally, Together for Short Lives (5), have defined palliative care for children as "An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement." They also looked at the different categories of children requiring palliative care as the spectrum and severity of a child's condition, complications and the impact on the child and their family need to be considered (see Table 1) (6). These categories help those providing palliative care services for children and their families to think about the different disease trajectories and when and where children may need support.

Global provision of children's palliative care

Palliative care for children is, for many, still a new concept, with provision of services being limited in many areas. A recent

Table 1: Examples of infectious diseases in patients presenting to various healthcare settings and RDTs available	
<p>Category 1 Life-threatening conditions for which curative treatment may be feasible but can fail</p>	<p>Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. <i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i></p>
<p>Category 2 Conditions where premature death is inevitable</p>	<p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. <i>Examples: cystic fibrosis, duchenne muscular dystrophy.</i></p>
<p>Category 3 Progressive conditions without curative treatment options</p>	<p>Treatment is exclusively palliative and may commonly extend over many years. <i>Examples: batten disease, mucopolysaccharidoses.</i></p>
<p>Category 4 Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death</p>	<p><i>Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury, complex healthcare needs, high risk of an unpredictable life-threatening event of episode.</i></p>
<p>Additional proposed categories (Wood et al):</p>	
<p>Category 5 Neonates with limited life expectancy</p>	
<p>Category 6 Members of a family having unexpectedly lost a child from a disease, an external cause or during the perinatal period</p>	

study looking at the global need for children’s palliative care estimates that at least 21.5 children globally need access to palliative care services, with at least 8 million of these needing specialist palliative care (7). Furthermore, initial analysis of need versus provision i.e. a gap analysis, suggests that in some countries such as Zimbabwe and Kenya, less than 1–5% of children in need can currently access services (8), with the global estimation being that less than 10% of children in need can currently access palliative care, i.e. there are over 19 million children globally who need palliative care but cannot access services. Thus, whilst it is estimated that only 6% of the overall global need for palliative care is for children (9), this still represents a global imperative for the development of children’s palliative care.

A systematic review published in 2011, identified that 65.6% of countries had no known children’s palliative care activity with only 5.7% having provision that was reaching mainstream providers (10). This review based on the levels of palliative care provision, developed by Clark and Wright (11) highlighted the need for urgent development of palliative care services for children, particularly noting the need for development within low- and middle-income countries, where need is often greatest, but provision non-existent. These findings were endorsed by Connor et al’s study (7) which found that the estimated need for children’s palliative care ranged from almost 120 per 10,000 children in Zimbabwe, a low-income country with high incidence of HIV, to that in a high income country such as the United Kingdom where approximately 20 per 10,000 children need access to palliative care. Whilst HIV is a key challenge for children’s palliative care, congenital

anomalies and neonatal conditions account for the greatest number of children in need of palliative care at the end of life (9), with those from cancer accounting for just 5.69% of the need at the end of life.

Whilst estimating the need and provision of children’s palliative care can be challenging, the International Children’s Palliative Care Network (ICPCN) has a directory of services globally, and estimates the provision of children’s palliative care (Figure 1). From this, ICPCN has been able to track the development of children’s palliative care globally, but it also shows the immense need for urgent and ongoing developments within the field across the majority of LMICs.

The International Children’s Palliative Care Network

The International Children’s Palliative Care Network (ICPCN) is a global network of individuals and organizations working in the field of palliative care for children. The vision of ICPCN is to achieve worldwide the best quality of life and care for children and young people with life limiting illnesses, their families and carers. Ensuring that children’s palliative care is acknowledged and respected as a unique discipline within healthcare systems and provided by suitably trained and qualified people to all children with life limiting or life threatening conditions and their families, regardless of where in the world they live. Care should include services, therapies and medications that will reduce pain and suffering and encompass all their physical, social, emotional, spiritual and developmental needs and that of their families, allowing for the best possible quality of life (12). ICPCN works in five key areas:

- ➔ Communication – with members, organizations,

Figure 1: An ICPCN map showing estimates of palliative care provision



policymakers etc. providing an international directory and mapping of services, networking opportunities, facilitating sharing of innovations and resources, provision of an up-to-date website providing a comprehensive source of information, editing the international children's edition of *e*hospice (website) and publishing resources and position papers on important issues related to children's palliative care.

- ➔ Advocacy – conducting advocacy at the national, international, regional and global levels depending on need and in conjunction with local and international partners. Representing children's palliative care in different fora such as the World Health Assembly, the WHO technical advisory group, the UN care and support task force, to name but a few.
- ➔ Research – co-ordinating and conducting research in different aspects of children's palliative care, such as children's understanding of illness, death and dying; the global need for children's palliative care; what makes a successful model for children's palliative care in sub-Saharan Africa; and studies looking at the 2-step vs 3-step analgesic ladder.
- ➔ Education – providing face-to-face training on children's palliative care, train the trainers and supporting the delivery of diploma, degree and masters' programmes. The provision of online e-learning training courses, endorsed by the University of South Wales and available in a variety of different languages. Covering topics such as pain assessment and management, communicating with children, bereavement, play, end-of-life care, and perinatal palliative care. Conferences are also held within LMICs, working with local partners, in order to promote the

advancement of children's palliative care in that region.

- ➔ Support and development – offering strategic support and materials to individuals and organizations wishing to start children's palliative care services in their part of the world, help and advice reintegration of services, models of care, etc.

Challenges for the development of CPC in LMICs

A variety of best practice models of children's palliative care in LMICs have been described e.g. Umodzi in Queen Elizabeth Hospital in Blantyre Malawi, Yayasan Rumah Rachel (Rachel House) in Jakarta Indonesia, and the Belarusian Children's Hospice (BCH) (13). However, many challenges exist in the development of palliative care for children in LMICs and these can be seen in relation to the public health approach to the development of palliative care (14) in the areas of policy, education, medication availability and implementation (13). These include:

- ➔ A lack of policies on palliative care generally and children's palliative care specifically.
- ➔ A lack of the recognition for the need of palliative care for children, and what palliative care can offer.
- ➔ A lack of the integration of palliative care for all ages, including neonates, children and young people, into the health system.
- ➔ A lack of access to education in the countries with the greatest need, alongside a lack of access to clinical sites for the modelling of children's palliative care, and a lack of access to specialist children's palliative care training
- ➔ A lack of access to medications for palliative care, in particular to that of moderate to severe pain relieving opioids, such as oral morphine. Where the Essential

Medicines List (EML) (15) for palliative care has been adopted, medicines may still not be available or accessible to the children in need, and evidence suggests that access to such medicines for children is poor (16).

- ➔ A lack of resources, such as financial, which impacts on the above.

Strategies for the development of CPC in LMICs

Whilst the greatest need for the development of children's palliative care is in LMICs, these are often the countries with least capacity for development, the most barriers to provision and the greatest health inequalities. The WHO sets out some basic principles for cancer control which can serve as a basis for implementing palliative care (1): leadership; involvement of stakeholders; creation of partnerships; responding to the needs of people; decision-making based on evidence; seeking continuous improvement; application of a systemic integrated approach; and adoption of a stepwise approach to planning and implementation. This framework is useful in reviewing some of the core infrastructure and services needed for the development of children's palliative care in LMICs.

- 1) **Leadership** – i.e. the activity of leading a group of people or an organization or the ability to do this (17). Leadership involves establishing a clear vision, sharing that vision with others so that they will follow; providing the information, knowledge and methods to realize the vision; co-ordinating and balancing conflicting interests of all members and stakeholders (17). Leadership has been, and remains key in the ongoing development of children's palliative care. Globally, there have been individuals, such as Ann Armstrong-Daly and Sister Frances Dominica and organizations, such as ICPCN, Children's Hospice International (CHI) and Together for Short Lives, who have been recognized as the leaders within the field. ICPCN seeks to work with individual leaders from different countries to support them to lead the development of children's palliative care within their country and region. Research into what are the components contributing to a successful model of children's palliative care in sub-Saharan Africa identified that having clear and strong leadership is essential, with leadership that is focused on the vision of children's palliative care, is passionate about the cause, and empowers and enables others to follow such that there is ongoing and lasting development (18). Likewise, changes in leadership along with a lack of leadership contribute to the challenges for models of children's palliative care.
- 2) **Involvement of stakeholders and creation of partnerships** – It is essential that we work together in partnership to achieve the aim of increasing access to and availability of

children's palliative care. Together we are stronger, and there are times when the ICPCN works in partnership with organizations working more broadly in palliative care, such as the International Association of Hospice and Palliative Care (IAHPC), the Worldwide Hospice and Palliative Care Alliance (WHPCA) and the Union International for Cancer Control (UICC), such as when working together to increase access and availability to the essential medicines for palliative care – both for adults and for children. By working in partnership on this issue we have a stronger voice, particularly as we note that only about 6% of global palliative care need is for children (9). Working in partnership also helps to foster an environment of mutual learning and mentorship where we can learn from each other and support each other. It is also important that developments are led from within country, thus the presence of local stakeholders is essential and ICPCN seeks to work through local, national and regional stakeholders as appropriate, thus fostering ownership and therefore ongoing sustainability of the development of children's palliative care services. Examples of partnerships include ICPCN working with World Child Cancer to support the development of CPC in Bangladesh, and also ICPCN working on an international forum with Childhood Cancer International, to promote and advocate for palliative care for all children with cancer.

- 3) **Responding to the needs of the people** – any palliative care service needs to respond to the palliative care needs of children and their families. Needs assessments have been carried out both in terms of the numbers of children needing palliative care within countries and the needs of children requiring palliative care e.g. in South Africa (19), in Ireland (20), in Serbia (21). Understanding need is linked to ensuring the services respond to the needs of the community, are in touch with the environment and have a clear vision.
- 4) **Decision-making based on evidence and seeking continuous improvement** – unfortunately there is a lack of evidence globally within children's palliative care. A review of the status of palliative care in children in sub-Saharan Africa, found that there is very little data within the field, particularly with regards to childhood cancers in Africa, models of children's palliative care and a general lack of an evidence base for children's palliative care, with no measurement tools (22). In 2012 new guidelines were published by the WHO with regards to the pharmacological treatment of persisting pain in children with medical illnesses (23). One of the challenges to the development of these guidelines was the lack of evidence on the use of medications in children's palliative care, with the WHO calling on organizations to undertake research and strengthen the evidence base within children's palliative care, with ICPCN being seen as a key stakeholder

in this (24). Global priorities for research on children's palliative care have been developed (25) and include areas around pain management, how to control pain in the absence of strong analgesics, models of palliative care development, and children's understanding of illness, death and dying – all areas of evidence important for the ongoing development of children's palliative care in LMICs. In the past, research has been seen as optional, however it is not and should be a core component of any children's palliative care services – indeed the less resources that we have, the more we need to know that we are using them in the best possible way, with the best possible outcomes. The need for a measurement tool to measure outcomes in children's palliative care has been recognized with the ongoing development of the APCA Children's Palliative Outcome Scale (APCAC-POS) (26, 27) which can be used both for research, but also for audit and ensuring continuous improvement.

5) **Application of a systemic integrated approach** – The importance of an integrated palliative care service was stressed within the World Health Assembly (WHA) resolution on palliative care. The resolution urges Member States to “support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care and universal coverage schemes” (p3 28). In the development of children's palliative care in LMICs there must be an integrated, co-ordinated approach. One that shows a clear strategy, is adaptable, consistent, provides different components of care through the holistic approach – all key elements that make an effective children's palliative care programme (18).

6) **Adoption of a stepwise approach to planning and implementation** – The WHA resolution (28) recognizes the need and ongoing challenges for the provision of palliative care for all ages and recommends that palliative care should be an integral component of all relevant global disease control and health system plans, including those relating to noncommunicable diseases (NCDs) such as cancer, and universal health coverage. Thus, there needs to be clear planning in place, clear policies and an implementation plan for the development and expansion of children's palliative care that is realistic, affordable and sustainable. Services can exist as stand-alone non-profit organizations, or be aligned in government-funded hospital or academic centres, and the development of beacon centres across the region can support both service development and education (29). Clear national and advocacy plans need to be developed in order to ensure the development and implementation of appropriate national policies, to ensure the availability

of the essential medicines for palliative care (30) including paediatric formulations, and to ensure the availability of appropriate education on children's palliative care at the different levels as identified in the WHA resolution (28), and in various education and competency documents such as the EAPC White Paper on core competencies for education in paediatric palliative care (31) and the APCA core competencies for palliative care in Africa (32). Education needs to be provided in a variety of forms such as through face-to-face training, clinical placements and online training, such as the ICPCN e-learning programmes (www.elearnicpcn.org), in order to ensure that education is available to all, regardless of where they live.

Conclusion

There is a great need globally for the ongoing development of children's palliative care, particularly within LMICs, and for children with cancer, alongside those with other conditions requiring palliative care. Barriers exist to the provision of CPC in LMICs but many of these can be overcome through clear advocacy, planning and implementation. Changes to such health inequalities can be addressed through the WHO framework, and the implementation of a comprehensive cancer control programme thus increasing access in LMICs. The ICPCN, the only network working together for the development of CPC globally, is in a unique position to support this ongoing development of CPC in LMICs in order that all children, regardless of where they live, will eventually have access to culturally appropriate palliative care provision. ■

Professor Julia Downing is an experienced palliative care nurse, educationalist and researcher. She has been working within palliative care for 25 years, with 17 of those working internationally in Uganda, Africa, Eastern Europe and throughout the world developing palliative care services for adults and children. She is the Chief Executive of the ICPCN and is an Honorary Professor at Makerere University, Kampala. She serves on the Boards of several NGOs and was the recipient of the Robert Tiffany lectureship from the ISNCC in 2014, was profiled in a publication on Women as Change Agents in Oncology and was awarded an Honorary fellowship from Cardiff University in 2016.

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in some of these countries.

Alex Daniels has worked in palliative care since 2010. As part of the Bigshoes team she provided hospital based palliative care for three Cape Town-based hospitals, including Red Cross War Memorial Children's Hospital. She played a key role in the development of an in-patient paediatric palliative care unit based at Sarah Fox Convalescent Children's Hospital in Cape Town. Alex has over 15 years of experience as a professional nurse and has considerable experience in facilitating grief and loss workshops with adult caregivers equipping them to support the bereavement needs of children. Alex joined ICPCN as education consultant in March 2017.

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